

# A Nurse's Eye-View on Health Literacy in Older Adults

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## Abstract

*Older adults are being asked to play a more active role in the management of their health, however low health literacy is pervasive in this population and is a major impediment to participation in healthcare activities. We sought to identify literacy-related challenges that older adults experience while managing their health. We interviewed 8 nurses who provided direct care to older adult populations. Thematic analysis was conducted exploring barriers, strategies and resources as they relate to health literacy in older adults. Three main themes were identified: literacy barriers, aging process and social resources. Problems associated with health literacy in this population were pervasive. Numeracy, a component of health literacy, was a central factor for a range of medication management problems. However, nurses reported that they were able to fashion solutions that enabled patients to comprehend quantitative information and act on it accordingly, resulting in better health management.*

## Introduction

Health literacy is a major international public health concern.<sup>1,2</sup> Health literacy is defined as: "The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."<sup>2</sup> Low health literacy is highly prevalent among older adults.<sup>3</sup> Disparities and gaps in access in the healthcare system necessitate that older adults play a more active role in the management of their health, and therefore ways to facilitate health literacy skills need to be sought.

## Background

More than 50% of all adults are challenged to comprehend instructions for taking their medications, understand their health plan and respond to public warnings.<sup>4,5</sup> Health literacy skills are needed for communicating with healthcare providers, reading and understanding health information, medication compliance, using medical devices, and making decisions about treatment options.<sup>6</sup> Inadequate health literacy is also associated with higher risk of hospitalization and greater resource use,<sup>7</sup> patient report of worse health status, and inadequate understanding of condition and treatment.<sup>8</sup> Low health literacy has a high prevalence among older adults, especially among ethnic minorities and those with lower socio-economic status, with estimated rates of literacy ranging from 25% to 80%.<sup>3,9</sup> In the United States (US) a large Spanish-speaking population receives health care from English speaking providers, which may further impact health literacy skills, especially for those who are older.

An important aspect of health literacy is health numeracy, "the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical, and probabilistic health information needed to make effective health decisions".<sup>9</sup> Ancker and Kaufman<sup>10</sup> articulate a framework explaining how health numeracy is constituted by a core set of skills and knowledge that inform all facets of interaction with the healthcare system. Evidence shows that health numeracy contributes to health disparities and negatively impacts health outcomes of those lower in literacy.<sup>9</sup> Low health literacy among seniors raises important concerns given that older adults use health care services more than other age groups.<sup>11</sup> Reducing health disparities caused by low health literacy requires a deeper understanding of older adults and their milieu. Specifically, it requires understanding barriers to participation in their health care, understanding the reasons for lower literacy rates, and identification of effective strategies for improving their ability to successfully navigate the healthcare environment, including strategies for eliminating obstacles and for identifying resources available for promoting better self-management.<sup>6</sup>

The objective of the research was to identify literacy-related challenges that older adults experience while managing their health. This study is part of a research program devoted to the development of an ecologically valid computer-based adaptive testing health literacy instrument for older adults. Interviewing front-line practitioners should enable us to develop realistic scenarios and tasks to populate our health literacy assessment instrument with a focus on health numeracy.<sup>10</sup> Specifically, it would elucidate the core components of health numeracy, such as basic

computation as they are manifested in real-world contexts. We interviewed nurses because they have close interactions with patients and first-hand knowledge of the literacy-related problems that they encounter.

## **Methods**

Semi-structured interviews were conducted with nurses who worked with an older adult population to gain insight into their perspectives regarding older adults and health management. Interviews were conducted with 8 nurses (2 male, 6 female), from varied health facilities located in New York City. Two nurses with Bachelor's degrees worked in an acute care program through the Visiting Nurse Services. The other 6 were Master's prepared nurse practitioners including a licensed geriatric and adult nurse practitioner, a wound care nurse and four adult nurse practitioners who were based in hospital clinics providing care to the geriatric population. A snowball sampling technique was used to identify additional participants.

Seven core questions were developed to elicit the clinician's perspectives on the barriers, resources, and strategies that older adults experience and use while managing their health: 1) "What are some of the potential barriers older adults face in managing their health?", 2) "What kinds of resources are available to older adults to aid in medication management?", 3) "What do you think older adults will perceive as barriers to managing the health care system?", 4) "What strategies do you have for overcoming these barriers?", 5) "Are there any activities you know of that older adults perform to manage their own health care?", 6) "Do your patients have problems following medication or treatment instructions? If yes, what are they?", 7) "What are potential barriers that contribute to health information seeking and decision-making for older adults?". Additional probing questions were asked to pursue emergent themes in more depth and detail. Stemming from these initial questions, further conversation discussed the literacy-related challenges within each question.

The study was approved by the Columbia University ethics board and informed consent was obtained before interviews commenced. Participants were ensured confidentiality and anonymity. All interviews were audio taped and transcribed verbatim. Interviews were carried out in the interviewee's office or the researcher's place of work. The interview sessions were conducted by two experienced qualitative researchers (LM & DK) and lasted approximately one hour each.

Thematic analysis was conducted on the transcripts. An open-coding analysis was performed using the qualitative software package NVivo8™(QSR International)<sup>12</sup> which was used to inductively develop codes and capture emergent themes. The researchers identified specific topics of interest and developed a subset of codes based on these themes. Responses were further refined into additional pre-defined codes related to our primary interest in literacy issues in older adult management of their healthcare, such as "literacy challenges" and "health literacy." Coding schemes were reviewed and revised iteratively by the research team. Specific codes were clustered into broader conceptual categories and themes, including predetermined ones that directly related to the goal of the study and emergent ones.<sup>12</sup>

Pertinent barriers were further categorized using a numeracy framework developed by Ancker and Kaufman<sup>10</sup> which posits that 8 factors contribute to a patient's ability to use quantitative information for health. Of relevance to this research are the three categories of individual level skills including basic quantitative skills, ability to use information artifacts (for example, navigating documents and understanding discharge instructions), and ability to communicate orally about quantitative health information.

## **Results**

Study participants provided multiple perspectives related to challenges faced by older adults. For example, the two visiting nurses in this sample provided vivid pictures of challenges with activities of daily living and management of health regimen in the patient's home, while the nurse practitioners, who provided in and out-patient care, described issues related to access to services as prescribed by Medicare and Medicaid.

The populations served by the sample of nurses were primarily Latino, but also included African American, Caribbean, Asian and Caucasian residents. The communities served by these practitioners were generally from the lower socio-economic strata. Only one of the nurses worked with a more affluent, mostly Caucasian population. Seven of eight interviewees raised concerns about the varying degree of health literacy among their patients and the impact that has on patients' ability to manage their health. Conversely, two of eight clinicians indicated that there are older adults who are quite capable of managing their health and come to appointments with questions about their medication and or disease related questions; however, these patients tend to be the younger of the older adults, with higher education, and better support systems.

Three themes mentioned most frequently that were central to our objectives related to health literacy barriers were identified: *literacy barriers*, *age-related issues* and *social resources*. *Literacy barriers* refer to basic literacy including reading, writing, and routine quantitative skills. *Age-related issues* covers all facets of change pertaining to age, and this theme emerged as a central mediator related to healthcare management in a population of older adults. *Social resources* refer to the range of support that individuals rely on for daily living.

*Literacy barriers* was the most general theme encompassing a range of societal and individual barriers. One practitioner said “*Sometimes we get people with very limited schooling with regards to reading and writing*”. The lack of rudimentary reading and writing skills was perceived by clinicians to be a significant impediment that is resistant to most solution strategies. Related ideas were expressed when one visiting nurse who described the importance of literacy relative to education or self-teaching stated, “*They will be taking [medications] that they have no idea why they are taking them, what it is supposed to do, whether or not it’s working, and how to tell if it’s working or not.*” Five subthemes related to literacy were identified, as shown in Table 1.

**Table 1.** Subthemes of Literacy Barriers in the Data

Subtheme	Explanation	Quotes
Basic Literacy Level	Participants tended to describe lack of basic reading skills as necessary to perform health-related tasks	“There is a substantial proportion who are illiterate even in Spanish, they cannot read or write even in their native language”
Embarrassment	Patients tended to be embarrassed by lack of literacy and will try to mask their problem	“We have a lot of problems with patients who use an excuse like I didn’t bring my glasses so I can’t read”; “They will bring family members to sign or read stuff for them”
Health Literacy	Some patients did not understand how basic health-related concepts operate	“Diabetes or hypertension is very complex. They are able to get their blood pressures measured on a regular basis but they don’t always remember to take their medications and they feel good so they don’t feel they need to take their medications”
Minimal formal education	Many of the older adults in this population were raised in countries with limited access to education	“Sometimes we get patients with very limited schooling”
Numeracy	Patients exhibit difficulty with basic computation and rudimentary numeracy. Participants tended to describe quantitative information as irrelevant to the elderly.	“A lot of them don’t know the milligrams that they are taking. That’s not important information, just what it is for and what it is”

*Age-related issues* was a commonly described theme, and included the following aspects: *fear of lower quality of life as one ages*, *onset of health problems*, *isolation*, *dependency*, *acute diagnosis*, and *social factors*. *Social resources* was a focal theme and viewed as a key factor in the success of healthcare management strategies. Several subthemes were identified including: *family support*, *visiting nurse service*, *assistance from clinician*, and *community support*. These subthemes represent different resources described by interviewees that may aid older adults in their health management process. Family support was cited as a resource by seven of eight participants. For example, one visiting nurse stated “*There are some people, especially people with supportive families that will help them. You will walk into some homes and there will be lists written out, this what you are taking*”. The converse is that absence of social resources represents a significant disadvantage for the literacy-limited older adult.

Interviewees emphasized the means by which low health literacy serves to exacerbate health management problems. One clinician noted that “*There are people who may not have had an 8<sup>th</sup> grade education or English is not their first language. Therefore, they have a harder time with health and managing the health aspects of their care*”. Another clinician vividly reflected on an experience with one of her patients: “*My patient was at home and had chest pains and shortness of breath. My patient did not call 911 because she ... didn’t know how to read the numbers on the telephone.*” A range of different strategies to overcome barriers were reported. For example, the clinician’s solution was to paint the number 0 in red nail polish so that her patient could know which numbers to press in the event of an emergency. Although this may be an extreme case of illiteracy, it highlights the profound literacy-related difficulties that some patients experience. Strategies such as the one described above depict the creative, real-life solutions clinicians develop to alleviate the barriers faced by older adults. Nurses would sometimes develop culturally-specific solutions to this problem. For example, one nurse characterized her efforts to educate individuals with diabetes from

the Latin Caribbean region. She would strategically use illustrations to depict portion control as a means to reduce carbohydrate intake without denying them culturally valued food products such as plantains

Of the 8 numeracy factors described by Ancker and Kaufman<sup>10</sup>, we identified 4 factors related to numeracy in this population (see Table 2). Numeracy problems were predominantly associated with medication management, but they were also mentioned in a range of contexts from following appointment schedules, understanding risk, and use of devices (from blood pressure monitors to telephones). According to these clinicians, basic computation presents a significant problem for providers because it is most difficult to fashion solutions for patients who lack rudimentary skills. Quantities are expressed in many different ways (both graphically and textually) in healthcare contexts, which can be very confusing for patients. In response to this, providers identify or create representations that are more comprehensible for the patients. Document literacy, which is the ability to use information embedded in complex text and non-text formats,<sup>10</sup> is subsumed by a range of sub-skills including reading comprehension. The notion that most healthcare documents are written at a level that supersedes the capabilities of many patients was identified.<sup>10</sup> Providing documents that are easier to comprehend can alleviate some of the difficulties that patients experience. Many of the patients seen by the Visiting Nurse Service were recently discharged from a hospital. The visiting nurse clinicians indicated that patients are often bewildered by the instructions or lack of instructions, especially as it relates to medication regimens. Clinicians stated that they perceived one aspect of the problem to be provider's communication. In particular, patients cannot use quantitative information effectively if providers fail to offer an adequate explanation that is communicated in a way that patients understand; however, the time constraints in typical care situations and lack of quality resources often limits clinicians' ability to provide adequate education.

**Table 2.** Categorization of barriers into numeracy challenges

Factors	Problem	Quotes
Basic Computation	Patients have difficulty with basic computation and rudimentary numeracy (recognizing numbers or quantities)	"A lot of them don't have a concept of the dose, that's my water pill. Do you know how many milligrams it is? No"
Representational fluency	Patients in this population are not able to identify representations of the same quantity	"They will say, I only had this much...I show them what is a portion size...I only had one plantain this morning ...I will show them that it's only just a 1/3 of what a portion size is. This really helps to show them...because if you say oh a 1/3 or a 1/2 you know, that's very hard for them to understand"
Document literacy	Information embedded in complex text and non-text format is not comprehensible.	"A lot of the time they get these prescriptions they don't know what they are for...when you go to the pharmacy they give you this huge print out of side effects they are not going to read, it's completely overwhelming".
Provider communication	Oral communication among provider and patient are not specific and can limit patient ability to manage treatment or health.	"The doctor says take a medication twice a day, they don't say to the patient take it every twelve hours. One patient said that his doctor prescribed a medication twice a day so he took the two pills at the same time to cut to the chase. What does once a day means? What does on an empty stomach means, twice a day, three times a day four times a day"

## Discussion

The objective of this study was to identify literacy-related challenges that older adults experience while managing their health. Nurses observed that health literacy problems are pervasive in older adults, which is consistent with other literature.<sup>3</sup> The interviewees expressed concern that older adults with limited health literacy experience poor health outcomes. Others have found that inadequate health literacy is a predictor of poor health outcome.<sup>8</sup> Furthermore, individuals with low health literacy can feel overwhelmed by their illnesses and difficulties in understanding their state of health may result in a lack of adherence.<sup>13</sup>

Although innumeracy is profound in this population, the nurses reported that they were able to fashion solutions that enabled certain patients to comprehend the quantitative information and act on it accordingly, resulting in better health management. Numeracy problems were typically related to medication management issues such as dosages and schedules. They also emerged in other contexts of varying complexity from managing appointment schedules to

understanding risk (e.g., decisions about surgery) and interpretation of results from monitoring devices such as blood pressure monitors and glucose meters. Representational fluency (i.e., understanding quantitative forms such as charts and tables) was also seen as a significant problem. This is consistent with other research that found that less numerate individuals were more likely to experience difficulty processing healthcare decisions.<sup>14,15</sup> Sheridan, Pignone, and Lewis, found that older adults were more susceptible to changes in the presentation of risk information.<sup>16</sup> In particular, those with lower numeracy skills were less likely to select the most effective treatment and were less able to calculate the relative benefits of a given treatment.

This formative study is characterized by several limitations, most notably the small sample size. In addition, although the gerontology nurses are instrumental in the delivery of healthcare to older adults, interviews with other providers would have offered a different perspective. In addition, interviewing and observing patients in the context of healthcare activities would further illuminate our understanding to barriers and solutions to health literacy problems. Although our focus was initially on cognitive issues pertaining to literacy, it was quite evident that these are inextricably intertwined with social, cultural and economic issues.

## Conclusion

The primary objective of our study is to gain a better understanding of the perspectives of gerontology nurse practitioners views on the world of older adults in the context of health. Although consumer health informatics interventions continue to proliferate, they have met with limited success with low literacy populations. In our view, a deeper understanding of the roots of the health literacy problem can make a significant difference in the efficacy of such interventions. In addition, frontline providers offer us valuable insights that can inform the development of an ecologically valid scenario-based health literacy assessment instrument.

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